

## **Written Testimony for the Public Health Committee**

### **Re: S.B. No. 437 (RAISED) AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS**

**For Monday, March 17, 2014**

My name is Jennifer Stroop. I am from Southington, CT. I am a board certified genetic counselor, with 18 years of experience. I have spent the past 13 years as a genetic counselor with the UCONN Hereditary Cancer Program. I am writing to voice my support for Bill 437.

I am grateful for the support of the Public Health Committee, and for Sen. Gerratana and Rep. Johnson for raising Bill 437. I support the modifications and comments on the bill that were shared with the committee chairs by our team of genetic counselors, geneticists, and other interested individuals.

There is a nationwide movement for genetic counselor licensure with 14 states currently issuing licenses (CA, DE, IL, IN, MA, NE, NM, OH, OK, PA, SD, TN, UT, WA)<sup>1</sup>, 4 additional states that have bills passed or in rulemaking (HI, NH, NJ, ND)<sup>1</sup>, and 7 states with bills introduced (FL, MI, MN, NY, RI, TX, WI).

**Genetic medicine is expanding rapidly and has an influence on many medical issues throughout the lifespan (including common disease like cancer and heart disease).**

- Advances in technology are decreasing the cost, increasing the availability, and increasing the complexity of genetic testing options and thus simultaneously increasing the complexity of the genetic counseling and testing process.<sup>2-4</sup>
- I have seen our program's referrals increase with the growing visibility of genetic testing through media attention (e.g. Angelina Jolie's disclosure that she carries a BRCA mutation and the Supreme Court decision to ban gene patents). I have also seen that increased visibility does not necessarily lead to increased understanding of the crucial issues in genetics for patients and their medical management.

**Specialized and current knowledge is critical for providing accurate genetic counseling and thus ensuring that patients reap the benefits of genetic technology.**

- Genetic counselors are professionals whose training includes graduate-level training, clinical experience and mandatory continuing education in genetics. They have expertise in genetics and genetic counseling and function as an essential member of the health care team.
- Numerous studies have demonstrated that non-genetics healthcare providers have little or no formal training in genetics, have inadequate knowledge of essential genetic concepts, and have insufficient knowledge and appreciation of the complex ethical and psychosocial issues involved in genetic counseling and testing.<sup>5-13</sup>
- The results of these studies are especially concerning as the complexity of this process increases with advances in technology.

**There is potential for harm if individuals represent themselves as genetic counselors without adequate levels of training and continuing education.**

- Patients rely on the advice of genetic counselors in making significant medical decisions including major prophylactic surgeries, decisions regarding the frequency and aggressiveness of preventative screenings for fatal diseases and decisions regarding testing during pregnancies. Genetic counselors also provide services that help individuals cope with the difficult pragmatic, emotional, ethical and social implications related to genetic testing.
- Several case series have now documented numerous cases (>50) of adverse events (including many in Connecticut) that have arisen when genetic counseling and/or testing occurred without the involvement of a certified genetics professional.<sup>14-16</sup> These included cases that resulted in advanced cancer diagnoses, unnecessary prophylactic surgeries, unnecessary expenditure of healthcare dollars that were charged to the insurance and/or patient, and psychological distress.<sup>14-16</sup>

I want to thank the Public Health Committee for raising a bill which would help protect consumers and ensure that genetic counselors are recognized as a profession. Genetics is an exciting field, and I am very lucky to work a state that has shown such strong support of genetics and biotechnology.

For these reasons, I strongly support S.B. No. 437 (RAISED) AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS.

Thank you for your consideration.

Sincerely,

Jennifer B. Stroop, M.S., C.G.C.

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